3-11-2021

Hospice Care for the Primary Physician

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HOSPICE CARE

FOR THE PRIMARY CLINICIAN

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PALLIATIVE CARE SERVICE

OBJECTIVES

- Palliative vs Hospice Care
- History of Hospice Care
- Description of the Hospice Benefit
- Review of Hospice Eligibility
- Discussing Hospice with your Patients

PALLIATIVE CARE AND HOSPICE – WHAT IS THE DIFFERENCE?

- Palliative Care
  - Palliative care is specialized medical care for people with serious illnesses.
  - It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.
  - The goal is to improve quality of life for both the patient and the family.
  - It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

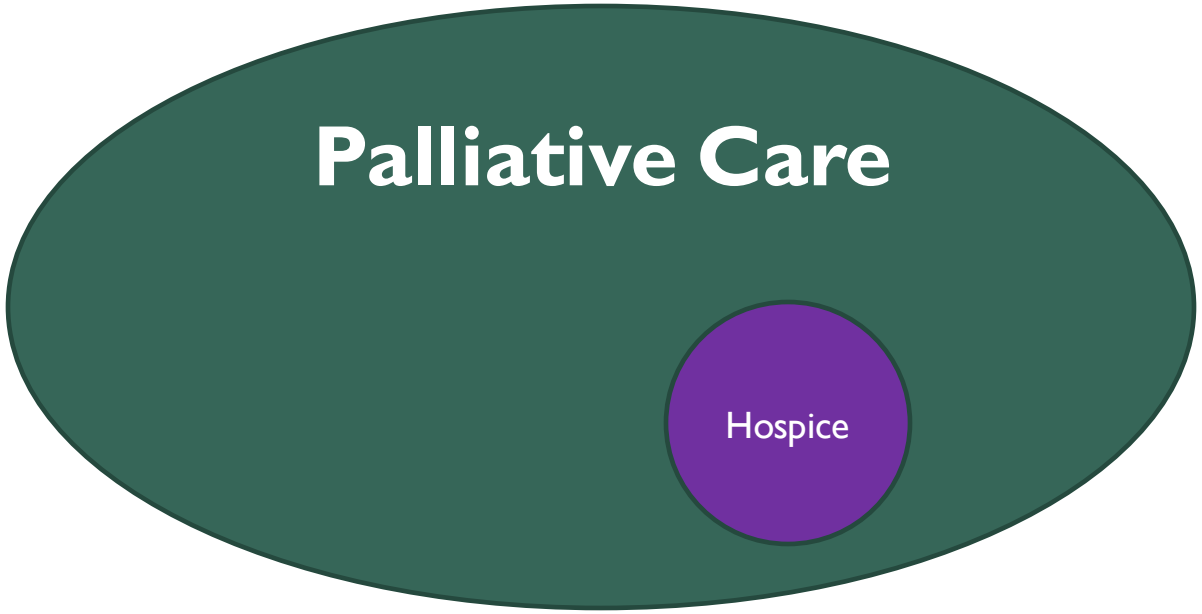
TABLE. Key Components of Palliative Care

Symptom management	Psychosocial-spiritual support	Decision making
Pain	Counseling	Prognostic awareness
Nausea	Social work	Advance care planning
Delirium	Pastoral care	Understanding of outcomes
Fatigue anorexia	Caregiver support	Defining quality of life
Anxiety depression	Bereavement	Eliciting values and goals

Understanding Palliative Care and Hospice: A Review for Primary Care Providers. Mayo Clinic Proceedings

PALLIATIVE CARE AND HOSPICE – WHAT IS THE DIFFERENCE?

- Hospice Care
  - Palliative Care for patients at the end of life who desire comfort-focused care



PALLIATIVE CARE AND HOSPICE – WHAT IS THE DIFFERENCE?

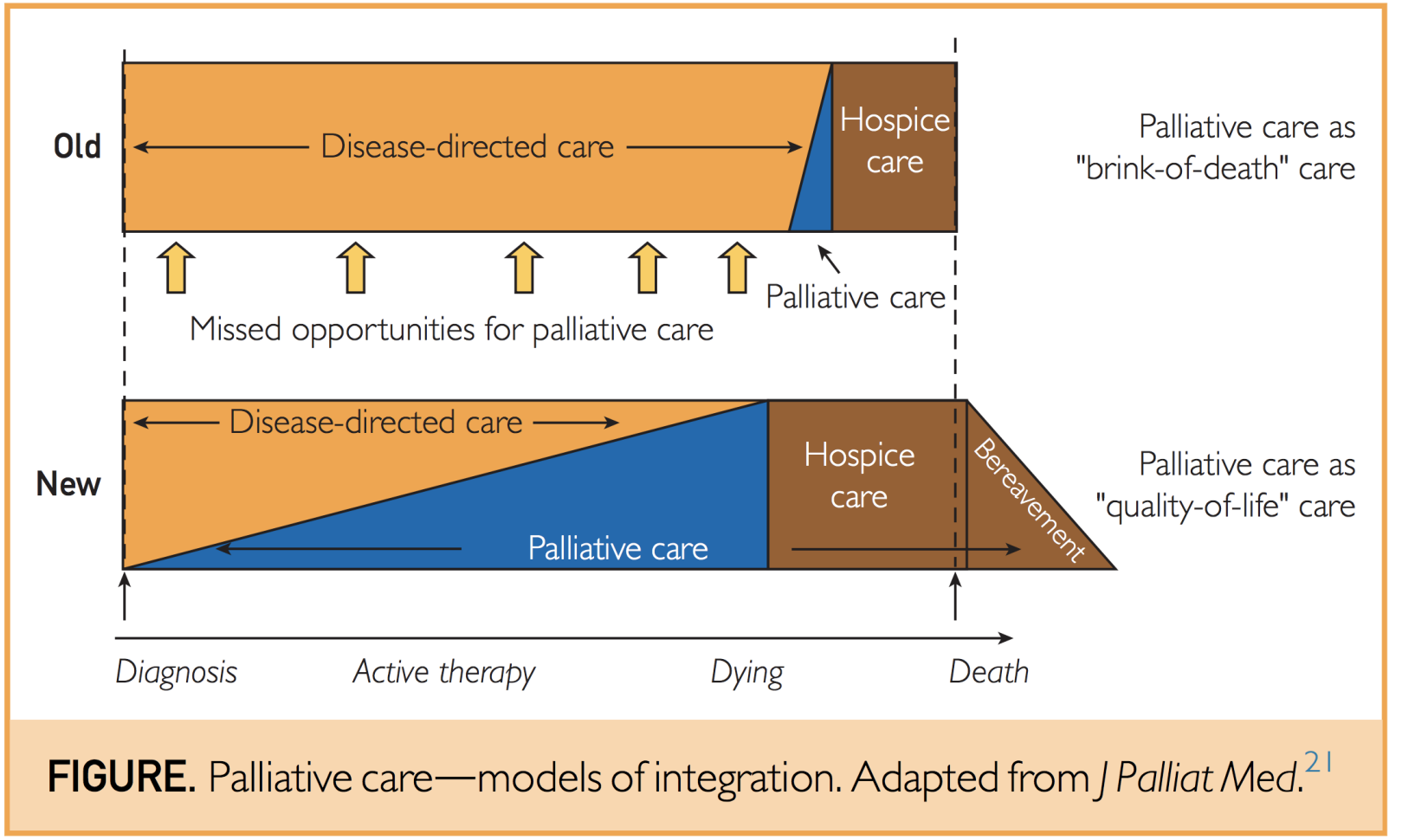
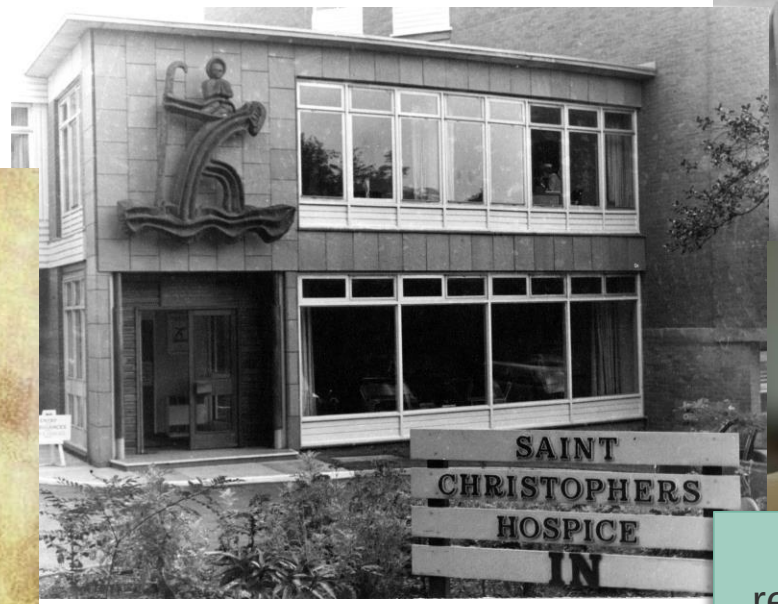


FIGURE. Palliative care—models of integration. Adapted from *J Palliat Med.*[21]

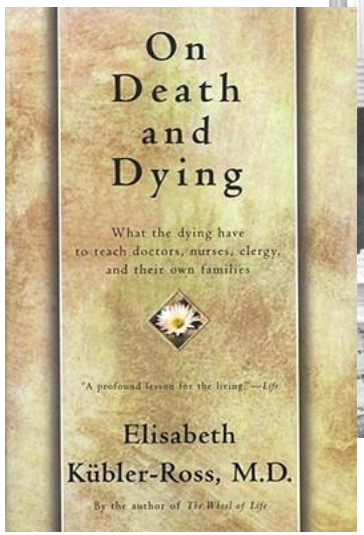
Understanding Palliative Care and Hospice: A Review for Primary Care Providers. Mayo Clinic Proceedings

HISTORY OF HOSPICE – A CARING ALTERNATIVE

- Dame Cicely Saunders – nurse, social worker, doctor (1918-2005)
  - 1948 – Nurse at Archway Hospital
  - 1967 – Established St Christopher's Hospice



- 1969 – On Death and Dying



In Latin "hospitium" means guesthouse

Dying people needed dignity, compassion, and respect as well as rigorous scientific methodology in the testing of medical treatments

HISTORY OF HOSPICE – A CARING ALTERNATIVE

- 1974 – Connecticut Hospice established
  - Florence Wald, RN , once the Dean of the Yale School of Nursing, became interested in end of life care after hearing Dame Saunders speak
  - **1968**: Wald took a sabbatical from Yale to work at St. Christopher's and learn all she can about hospice.
  - **1974**: Florence Wald, along with two pediatricians and a chaplain, founded Connecticut Hospice in Branford, Connecticut.

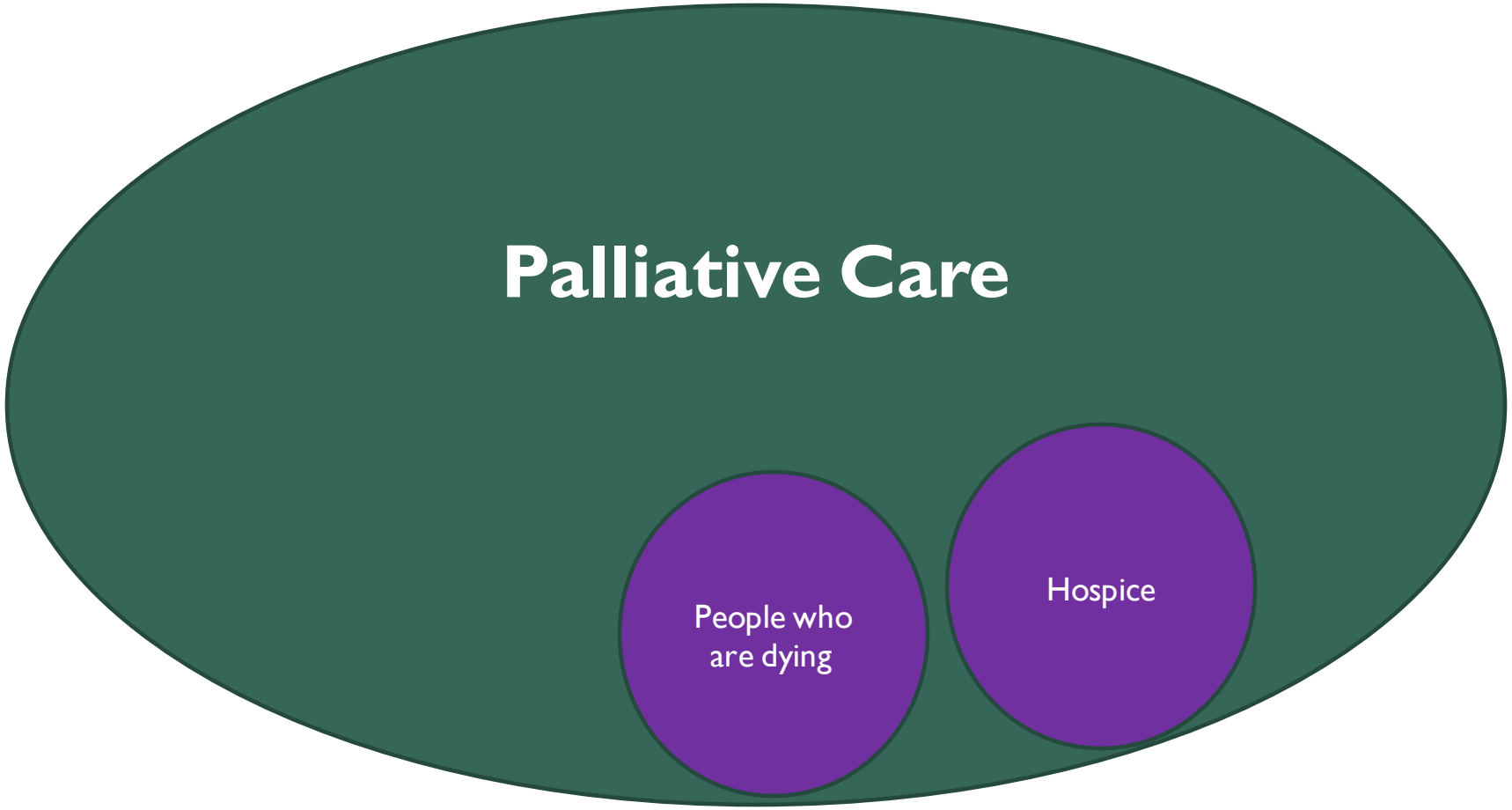
HISTORY OF HOSPICE – A CARING ALTERNATIVE

- 1978 – US Dept of Health, Education, and Welfare task force reported the movement of hospice to be a "viable concept" worthy of federal support
- 1983.- President Reagan signed the Medicare Hospice Benefit into law. This covers 80-85% of hospice beneficiaries
- 1993 – President Clinton's health care reform made hospice a nationally guaranteed benefit
- 2010 – Cicely Saunders Institute opens at Kings College London to focus on palliative care practice, research, and education.
- 2018 – per Medicare there are 4,639 hospices in operation in the US caring for 1.55 million Medicare patients

NHPCO Facts and Figures 2020 Edition

HOSPICE CARE IS _____

- A philosophy of care
- An insurance benefit
- A choice to use this care
  - Focusing on quality of life for the terminally ill
  - Forgoing certain life-prolonging therapies

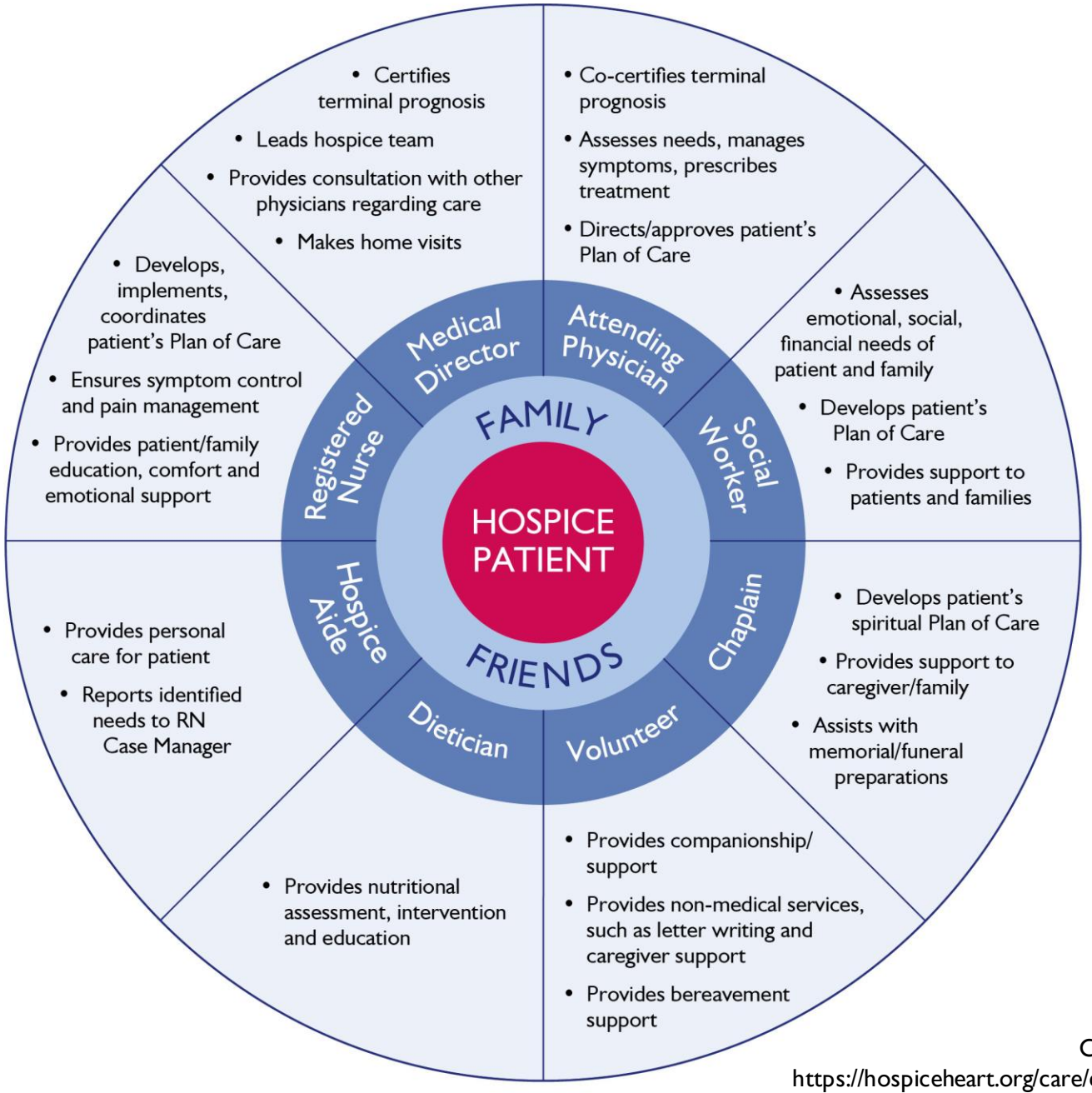

Palliative Care
People who are dying
Hospice

HOSPICE CARE

- Terminally ill = "individual has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs it's normal course."
- Care is:
  - Individualized
  - Multidisciplinary
  - Non-curative
  - Home-based (typically), centered on patient and family unit
  - Provided without out of pocket costs/co-pay
  - Responsive 24/7
  - Shown to provide better pain management and symptoms control, higher perceived quality of care for emotional needs

HOSPICE CARE

- Team:
  - Physician
  - Medical Director
  - Nurse
  - Social Worker
  - Home Health Aide
  - Chaplain
  - Volunteers



Circle of Care
https://hospiceheart.org/care/circle-of-care/

HOSPICE CARE

- Services Provided:
  - Management of Pain and other symptoms
  - Assists the patient and family members with the emotional, psychosocial, and spiritual aspects of dying
  - Provides medications and medical equipment
  - Instructs the family on how to care for the patient
  - Provides grief support and counseling
  - Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
  - Delivers special services like speech and physical therapy when needed
  - Provides grief support and counseling to surviving family and friends

HOSPICE CARE

- Locations of Service/Levels of Care:
  - Home / Routine Hospice Care (RHC, 98.2%) = most common level, services provided at the patient residence or SNF (if residing there). All physical care done by family or privately paid aide(s)
  - General Inpatient Care (GIP, 1.2%) = short term level of care provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. Can be located at a hospital, hospice unit, SNF, or at home with CHC
  - Continuous Home Care (CHC, 0.2%) = care provided at home for between 8 and 24 hours a day to manage pain and other acute medical symptoms.
  - Inpatient Respite Care (IRC, 0.3%) = patient transfer to inpatient level to provide temporary relief to the patient's primary caregiver. Available for 5 days at a time

NHPCO Facts and Figures 2020 Edition

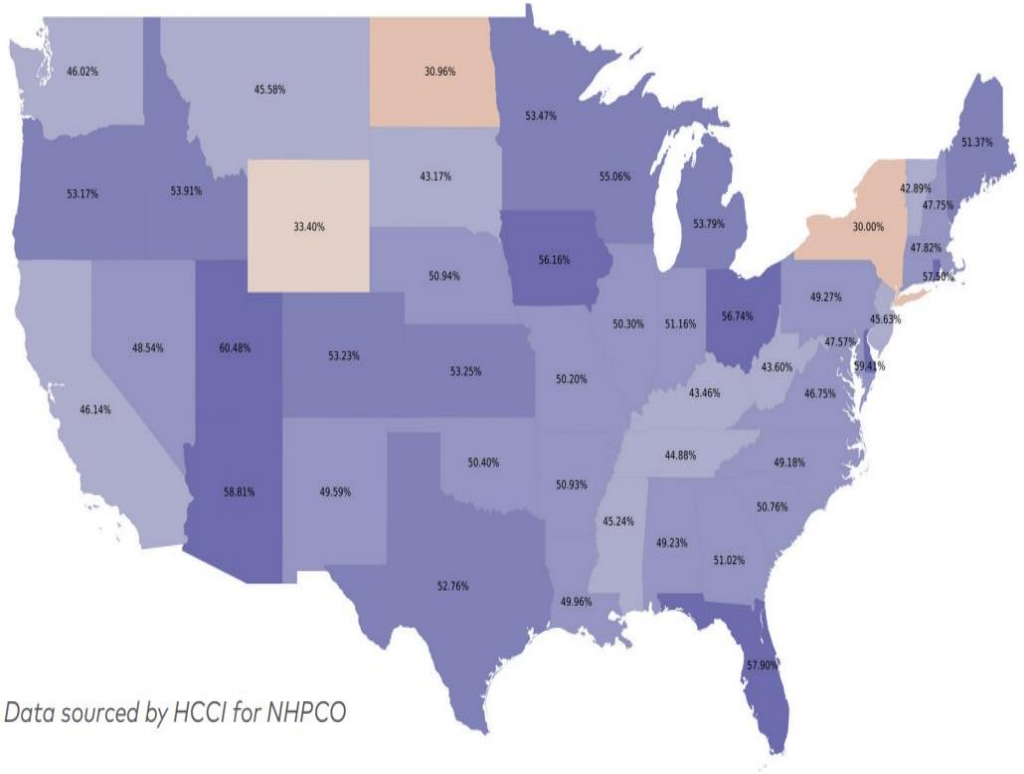
HOSPICE CARE

- GIP Indications:
  - Pain or symptom crisis not managed by changes in treatment in the current setting or that requires frequent medication adjustments and monitoring
  - Intractable nausea/vomiting
  - Advanced open wounds requiring changes in treatment and close monitoring
  - Unmanageable respiratory distress
  - Delirium with behavior issues
  - Sudden decline necessitating intensive nursing intervention
  - Imminent death – only if skilled nursing needs are present

www.nhpco.org/sites/default/files/public/regulatory/GIP_Tip_GIP_Sheet.pdf

HOSPICE CARE

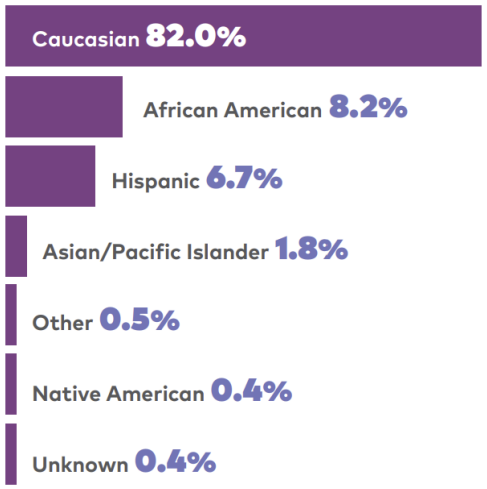
Figure 4: % of Medicare Decedents Served by Hospice by state *(Aligns with Figure 5)*



Source: CMS Data sourced by HCCI for NHPCO

- In 2018:
  - 1.55 million Medicare beneficiaries were enrolled in hospice for one day or more
  - Of all Medicare decedents 50.7% were enrolled in hospice at time of death

Figure 9: % of Patients by Race for 2018



Source: CMS Data sourced by HCCI for NHPCO

HOSPICE CARE

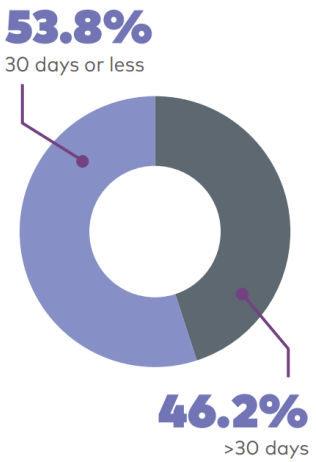
- ***Average Length of Service:*** 89 days
- ***Median Length of Service:*** 18 days
- ***Days of Care:*** total of 114 million days of care paid for by Medicare.

How Much Care Is Received (continued)

Days of Care

In 2018 over half (53.8%) of patients were enrolled in hospice for 30 or fewer days.

Figure 13: % of Patients by Days of Care for 2018

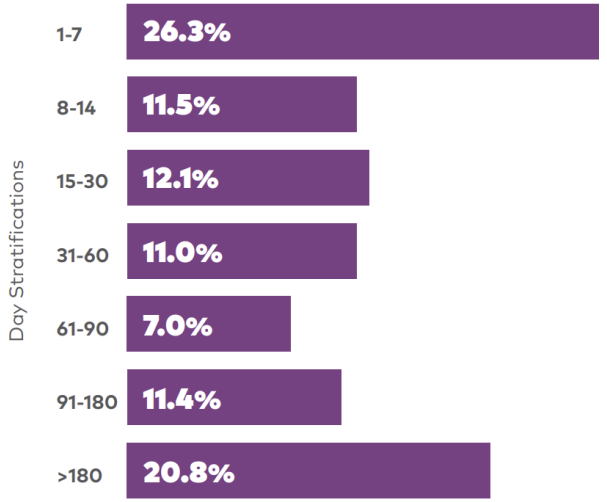


Source: CMS Data sourced by HCCI for NHPCO

Days of Care

Days of care over multiple years by percentage of patients*

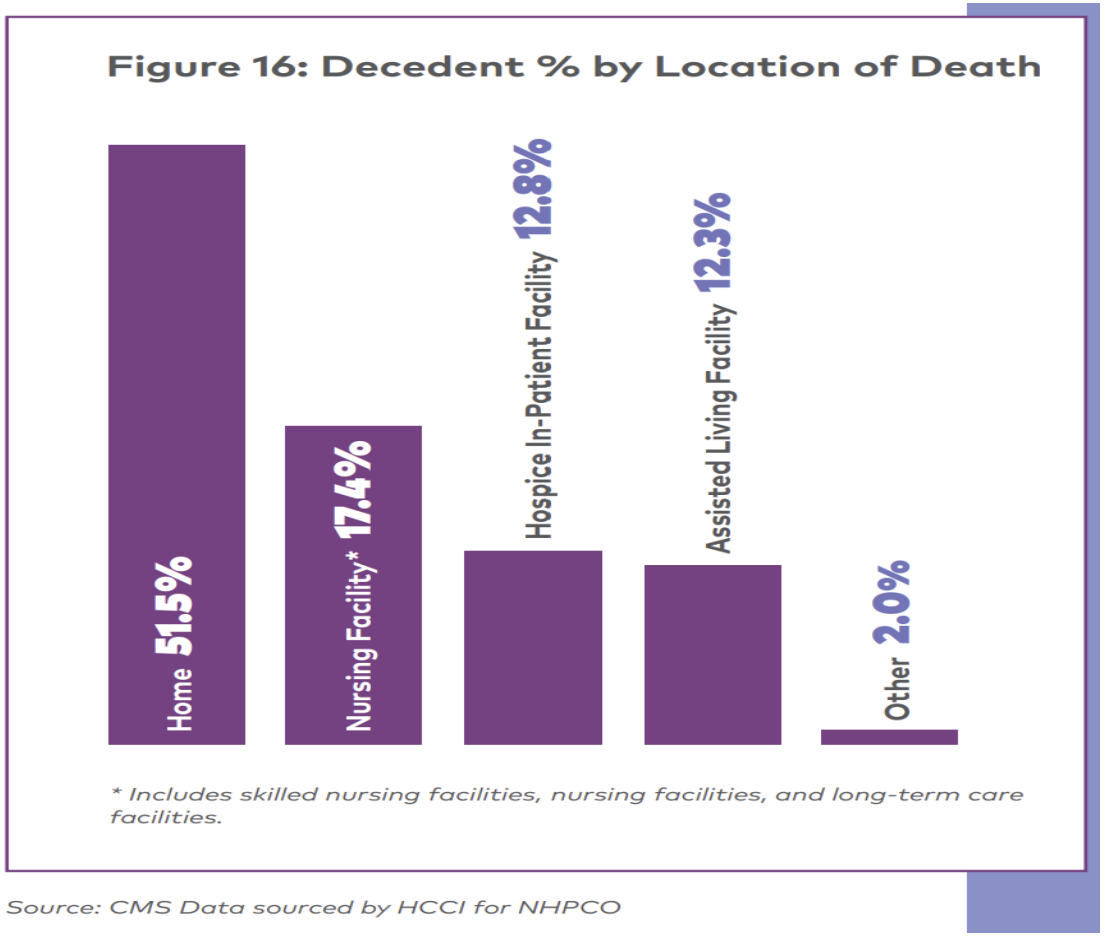
Figure 14: Days of Care Between 2016-2018 by % of Patients



**These values are computed using all days of care that occurred between 2016 through 2018 highlighting extended care beyond 180 days that covered multiple years vs just 2018.*

Source: CMS Data sourced by HCCI for NHPCO

HOSPICE CARE



http://flvns.org/pages/hospicecare/
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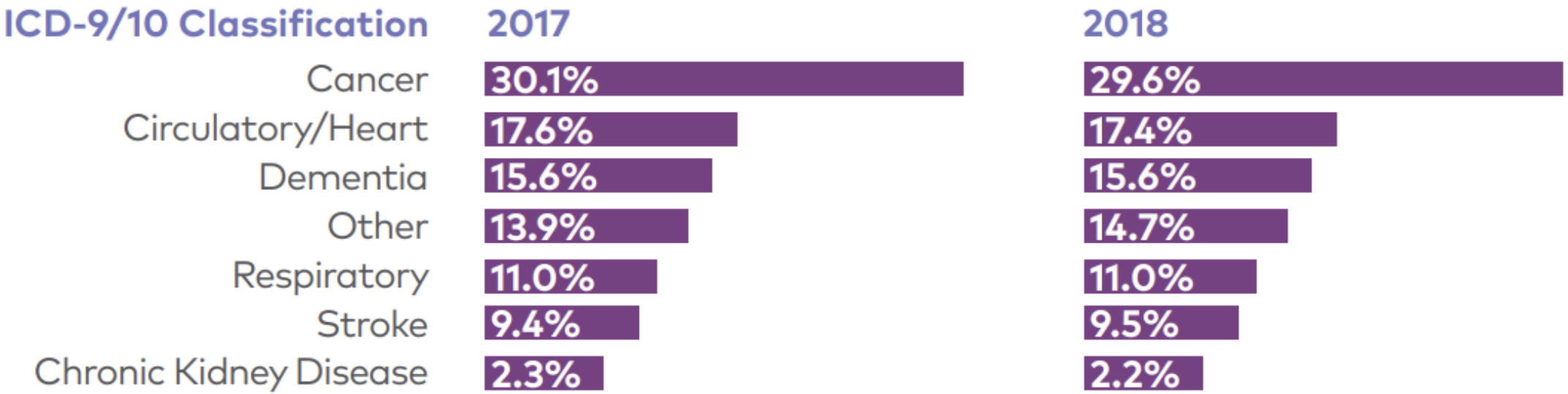
HOSPICE CARE

Figure 10: % of Hospice Decedents by Principal Diagnosis for 2017 & 2018



HOSPICE ADMISSION CRITERIA

PATIENT SHOULD MEET ALL OF THE FOLLOWING CRITERIA:

- Terminal condition either due to a specific diagnosis or a combination of diseases
- Nurse or physician assessment documented clinical progression of disease process including laboratory, radiology or other studies
- Patient/Family/Physician agrees exacerbation of terminal illness will not be treated agressively
- Patient and/or Family have chosen a course of palliative care

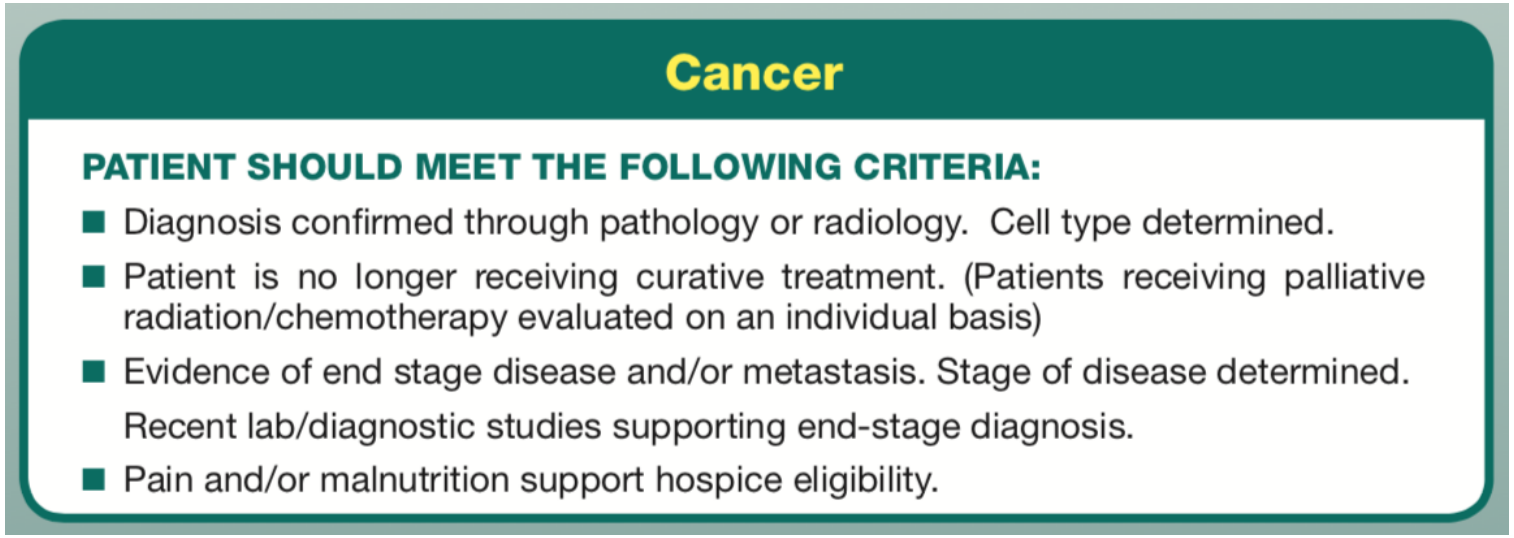
SUPPORTIVE DOCUMENTATION:

- Unintentional, progressive weight loss greater than 10% of body weight
- Multiple ER visits or hospitalizations over the previous 6 months
- Functional decline (Karnofsky Performance Status less than or equal to 50% or dependence in 3 ADL's)
- Serum Albumin less than 2.5 gm/dl
- Combination of serum cholesterol under 156 and hematocrit less than 41%

Table 1. Karnofsky Performance Scale Index (KPS)

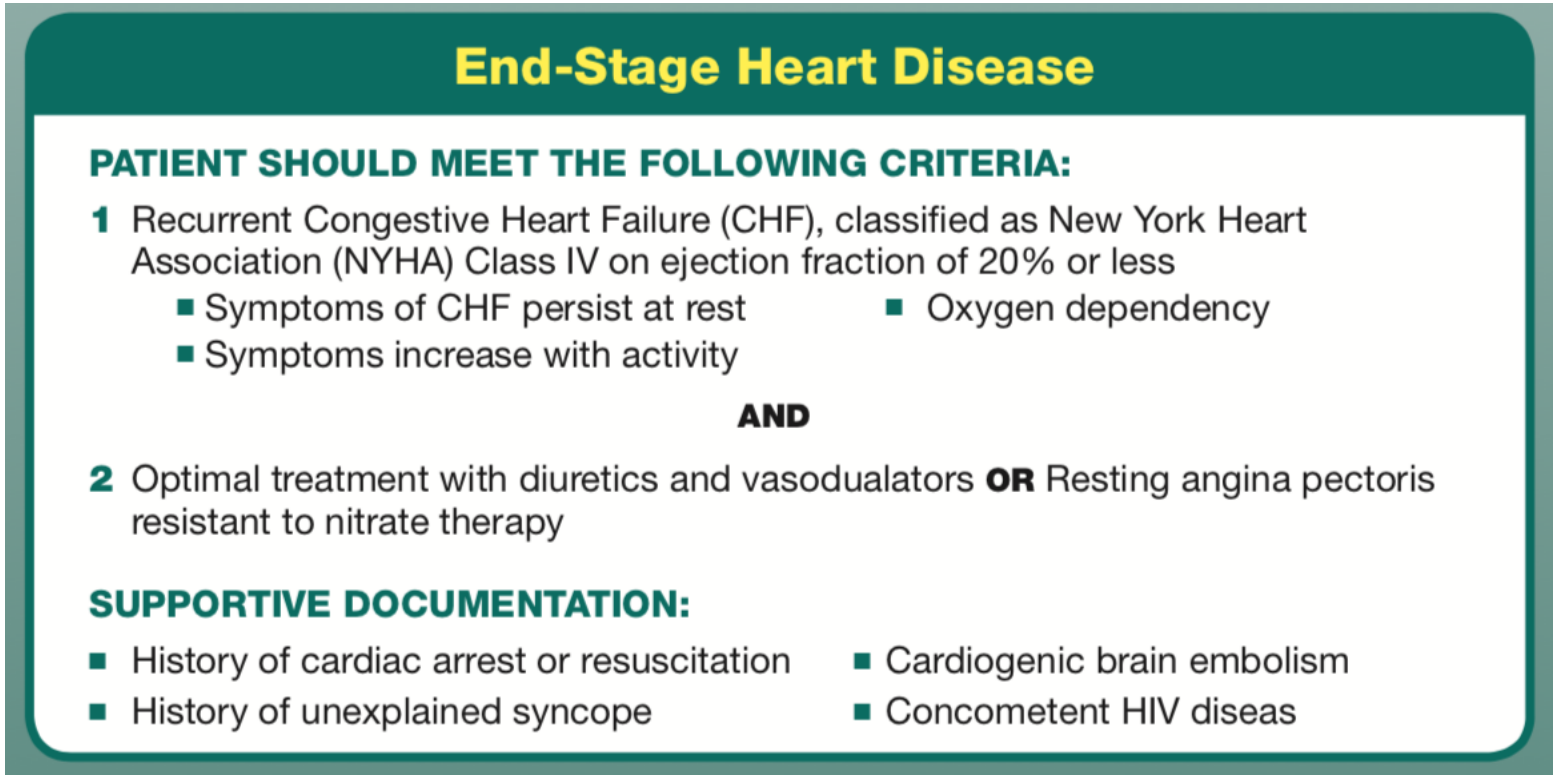
Score (category)	Karnofsky
100	Normal; no complaints; no evidence of disease.
90	Able to carry on normal activity; minor signs or symptoms.
80	Normal activity with effort; some signs or symptoms of disease.
70	Care for self; unable to carry on normal activity or to do active work.
60	Requires occasional assistance but is able to care for most of his needs.
50	Requires considerable assistance and frequent medical care.
40	Disabled; requires special care and assistance.
30	Severely disabled; hospitalization necessary; active supportive treatment is necessary.
20	Very sick; hospitalization necessary; active supportive treatment is necessary.
10	Moribund; fatal processes progressing rapidly.
0	Dead.

HOSPICE ADMISSION CRITERIA



- Poor functional status: "How much time do you spend in a chair or laying down?" >50% ~ 3mon
- Other cancer syndromes:
  - Malignant hypercalcemia: 8 weeks, except newly diagnosed breast cancer or myeloma
  - Carcinomatous meningitis: 8–12 weeks
  - Multiple brain metastases: 1–2 months without radiation; 3–6 months with radiation
  - Malignant ascites, malignant plural effusion or malignant bowel obstruction: <6 months

HOSPICE ADMISSION CRITERIA



End-Stage Heart Disease

PATIENT SHOULD MEET THE FOLLOWING CRITERIA:

1 Recurrent Congestive Heart Failure (CHF), classified as New York Heart Association (NYHA) Class IV on ejection fraction of 20% or less

- Symptoms of CHF persist at rest
- Symptoms increase with activity
- Oxygen dependency

AND

2 Optimal treatment with diuretics and vasodualators **OR** Resting angina pectoris resistant to nitrate therapy

SUPPORTIVE DOCUMENTATION:

- History of cardiac arrest or resuscitation
- History of unexplained syncope
- Cardiogenic brain embolism
- Concometent HIV diseas

- Bed to chair existence
- Symptomatic despite maximal medical management
- On inotropes asking to avoid readmissions
- Not candidate or declines invasive procedures

HOSPICE ADMISSION CRITERIA

Alzheimer's / Dementia

At or beyond Stage Seven on the Functional Assessment Staging (F.A.S.T.)

PATIENT SHOULD SHOW ALL OF THE FOLLOWING CHARACTERISTICS:

- Inability to perform ADL's without assistance
- Speech is limited to approximately six or fewer words
- Nonabulatory
- Urinary and fecal incontinence

SUPPORTING MEDICAL COMORBID OR SECONDARY CONDITIONS:

- Aspiration pneumonia
- Fever recurrent after antibiotics
- CHD
- COPD
- Pyelonephritis: or other upper urinary tract infections
- Septicemia and decubitus ulcers
- Difficulty swallowing food or refusal to eat
- Patients receiving tube feedings should have documented impaired nutritional status

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless super-vised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

HOSPICE ADMISSION CRITERIA

Stroke and Coma

PATIENT SHOULD MEET ALL OF THE FOLLOWING CRITERIA:

STROKE

1 Palliative Performance Scale (PPS) of 40
- Primarily bed bound
- Inability to perform ADL's without assistance
- Reduces food/fluid intake

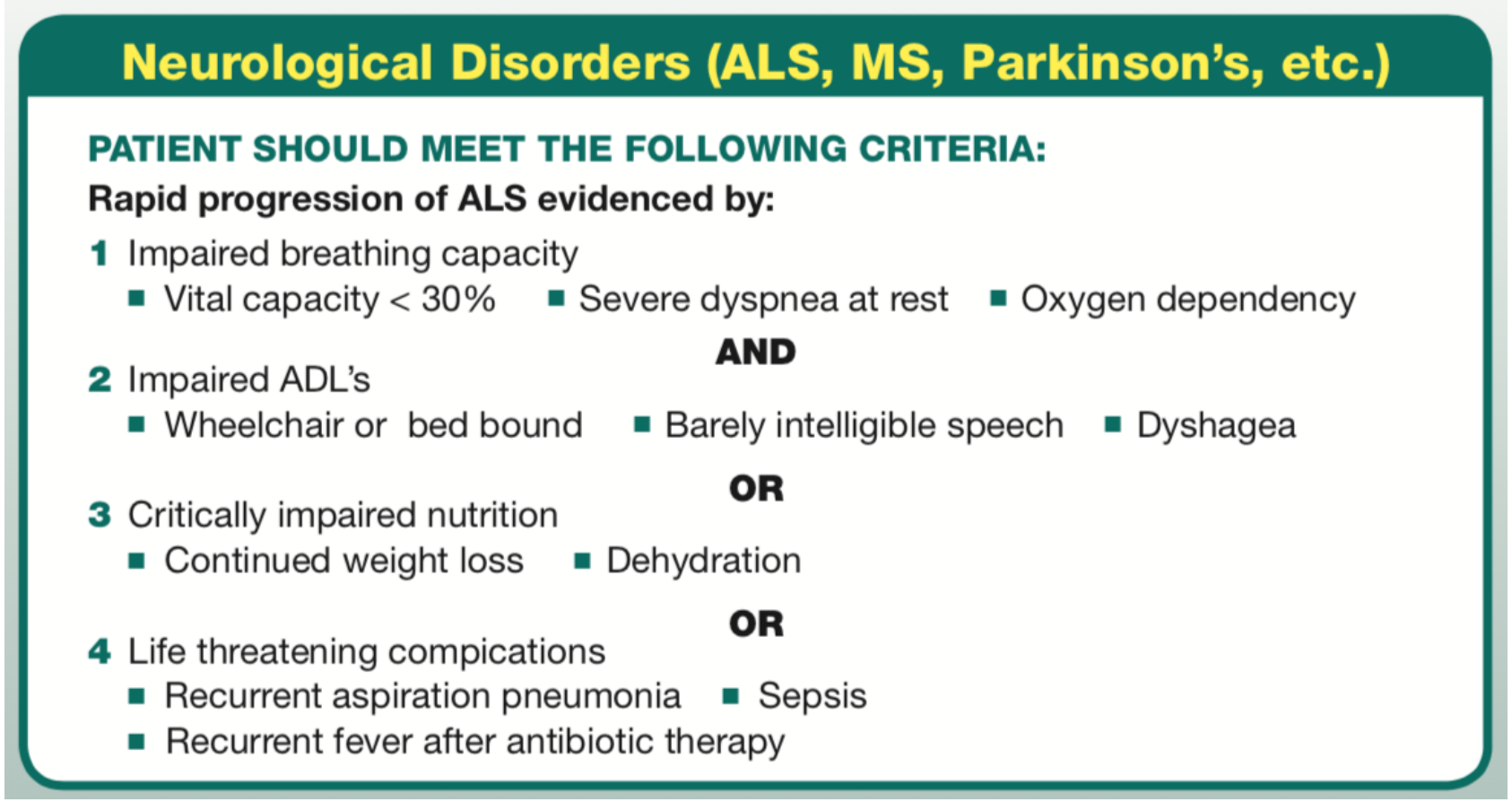
2 Inability to maintain hydration and caloric intake with one of the following:
- Weight loss 10%
- Serum Albumin 2.5 gm/dl
- History of aspiration

COMA

Comatose patient with any three of the following on day 3 of coma:
- Abnormal brain stem response
- Absent verbal response
- Absent withdrawal response to pain
- Serum creatinine > 1.5 mg/dl

- May choose to continue artificial nutrition only if other evidence of comorbid terminal illness and choosing comfort-focused treatments

HOSPICE ADMISSION CRITERIA



Neurological Disorders (ALS, MS, Parkinson's, etc.)

PATIENT SHOULD MEET THE FOLLOWING CRITERIA:

Rapid progression of ALS evidenced by:

1 Impaired breathing capacity
- Vital capacity < 30%
- Severe dyspnea at rest
- Oxygen dependency

AND

2 Impaired ADL's
- Wheelchair or bed bound
- Barely intelligible speech
- Dyshagea

OR

3 Critically impaired nutrition
- Continued weight loss
- Dehydration

OR

4 Life threatening compications
- Recurrent aspiration pneumonia
- Sepsis
- Recurrent fever after antibiotic therapy

- Deciding not to use mechanical ventilation, +/- artificial nutrition

HOSPICE ADMISSION CRITERIA

- Lab findings:
  - FEV1 ≤ 30% expected post-bronchodilator
  - Serial decrease in FEV1 of at least 40 mL/yr over several years
  - PO2 ≤ 55 on room air
  - O2 Sat ≤ 88% on room air
  - PCO2 ≥ 50

Pulmonary Disease

PATIENT SHOULD MEET THE FOLLOWING CRITERIA:

1. Disabling dyspnea at rest
2. Dyspnea exacerbated by other debilitating symptoms such as fatigue and cough
3. Frequent ER visits or hospitalizations for pulmonary infections and/or respiratory failure

SUPPORTIVE DOCUMENTATION:

- Presence of Cor Pulmonale or Right-sided Heart Failure (due to advanced pulmonary disease) documented by Echocardiogram, EKG, CXR, physical signs of CHF
- Unintentional, progressive weight loss of greater than 10% of body weight over the preceding six months
- Resting tachycardia greater than 100/minute in a patient with known COPD
- Hypoxemia and/or Hypercapnia at rest while on oxygen

HOSPICE ADMISSION CRITERIA

End-Stage Renal Disease

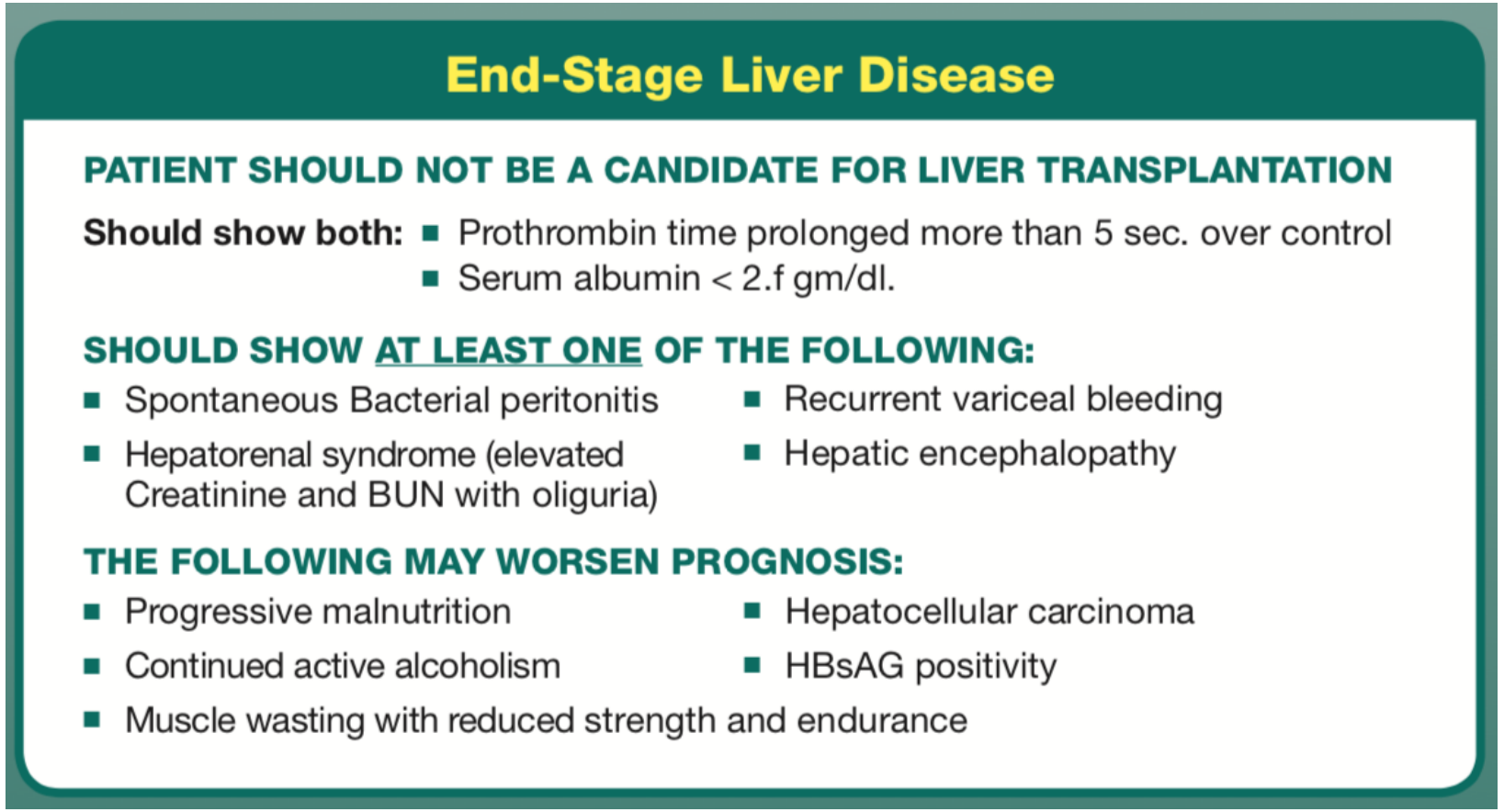
PATIENT SHOULD MEET THE FOLLOWING CRITERIA:

1. Dicontinuing or refusing dialysis
2. Creatinine clearance of < 10 cc/min (< 15 cc/min for diabetics)
3. Serum Creatinine > 8.0 mg/dl (> 6.0 mg/dl for diabetics)

SUPPORTIVE DOCUMENTATION:

- Hepatorenal syndrome
- Uremia
- Oliguria (<400 cc/day)
- Intractable hyperkalemia (>7.0)
- Uremic pericarditis
- Intractable fluid overload

HOSPICE ADMISSION CRITERIA



End-Stage Liver Disease

PATIENT SHOULD NOT BE A CANDIDATE FOR LIVER TRANSPLANTATION

Should show both:
- Prothrombin time prolonged more than 5 sec. over control
- Serum albumin < 2.f gm/dl.

SHOULD SHOW AT LEAST ONE OF THE FOLLOWING:
- Spontaneous Bacterial peritonitis
- Hepatorenal syndrome (elevated Creatinine and BUN with oliguria)
- Recurrent variceal bleeding
- Hepatic encephalopathy

THE FOLLOWING MAY WORSEN PROGNOSIS:
- Progressive malnutrition
- Continued active alcoholism
- Muscle wasting with reduced strength and endurance
- Hepatocellular carcinoma
- HBsAG positivity

- Progressive functional decline, mainly sit/lie
- Refractory ascites

HOSPICE ADMISSION CRITERIA

End-Stage AIDS

PATIENT SHOULD HAVE BOTH OF THE FOLLOWING:

1 CD4 less than 25 cells/mcL

AND

2 Persistent HIV RNA (viral load) of >100,000 copies/ml

AND ONE OF THE FOLLOWING:

1
- CNS lymphoma (2.5 months)
- MAC bacteremia, untreated/ unresponsive
- Renal failure in absence of dialysis
- Progressive multifocal leuko-encephalopathy
- Untreated/unresponsive wasting
- Visceral Kaposi's sarcoma unresponsive to therapy
- Crytosporidium infection
- Toxoplasmosis unresponsive to treatment

OR

2
- Declining functional status as evidenced by Karnofsky Performance Status (KPS) ≤ 50%

SUPPORTIVE DOCUMENTATION:

- Chronic persistent diarrhea for one year
- Decisions to forego antiretroviral, chemotherapeutic and prophylactic drug therapy related specifically to HIV disease
- Congestive heart failure, symptomatic at rest
- Persistent serum albumin <2.5 gm/dl
- Concomitant substance abuse
- Advanced AIDS dementia

- Ensure patient had opportunity to have care by HIV specialist

HOSPICE FOR PRIMARY CARE – WHEN TO REFER

- When to refer:
  - Eligible: "Would I be surprised if this person died in the next 6 months?"
    - Are patient and family aware of end stage incurable disease?
  - Beneficial: "Would hospice care be beneficial to this person?"
    - High symptom burden/care needs but accessing routine care increasingly difficult
    - Frequent hospitalizations becoming less beneficial
    - Expressed wishes to be cared for at home, die at home, would be at peace if it was their time
    - Either not being offered disease-modifying/life-prolonging therapies or is wanting to stop them

HOSPICE FOR PRIMARY CARE – WHEN TO REFER

- If you got sick, how would you want to be treated?
- If you were so sick you were dying, where would you want to be taken care of?

HOSPICE FOR PRIMARY CARE – WHEN TO REFER

- A recommendation from primary doctor is powerful
  - NOT abandonment – can stay involved or is referral to specialty care
- Referral – can be done by anyone connected to the patient

HOSPICE MYTHS

- Hospice is giving up
- Hospice is only for people in pain
- Hospice is only for the last days of life
- Hospice is a place you can stay until you die
- Hospice provides a home nurse 24/7
- Hospice is only for cancer patients & old people
- Hospice means you stop all medications for all conditions
- Hospice means there's no turning back, never going to the hospital
- Hospice makes you be DNR
- Hospice makes you die faster
- Hospice lets people starve
- Hospice starts the morphine drip and just turns it up
- Hospice makes you die within 6 months
- Hospice care ends after the person dies

FINAL TIPS

- Uninsured – hospices provide charity care hospice at home
- Lives alone – still refer, but this can be a barrier. Consider residential?
- Patient/family unsure – consider referring for an informational visit at home, no obligation
- Unhappy with previous hospice experience – can change companies at anytime.
- Don't promise an inpatient stay, promise an assessment

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- *"Circle of Care" https://hospiceheart.org/care/circle-of-care/*